**Can We Still Call it Evidence-Based Practice if We Deviate From the Evidence?**

Presented by Marcel Dijkers

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>> JOANN STARKS: Hello and welcome to today's Webcast brought to you by the Center on Knowledge Translation for Disability and Rehabilitation Research or KTDRR for American Institute to Research. The Center on KTDRR is funded by the National Institute on Disability, Independent Living and Rehabilitation Research known as NIDILRR in the U.S. Health and Human Services.

I'm Joann Starks with the Austin office of American Institute of Research, AIR. I also want to thank some of my colleagues who are helping with today's event, Ann Outlaw and Steven Boydston. The Webcast is being recorded. Most people confirmed they are okay with it being recorded. But if you do not want to be recorded, be sure you don't make any comments or ask any questions in the chat box.

In this Webcast Dr. Marcel Dijkers will share information and lead a discussion on the limits of evidence‑based practice, especially when an intervention is not implemented exactly or with the same population in the same context as it was developed. This is a topic of interest that was identified by members of the community of practice on evidence and disability in rehabilitation research. Before we start I want to point out that we do have CART services available. The link is posted in the lower right‑hand corner of the screen.

Next I will review some basic features of the Adobe Connect platform. You should be listening to the presentation through your computer speakers. You can use your own computer audio settings to increase the volume. There is also a speaker icon in the control bar at the top left‑hand side of the screen. This icon is green when it is active. You can also adjust the volume using the arrow next to the speaker icon. The presentation slides are in the center of the screen. On the bottom right side is a box labeled links. You can browse to the links for CART services and visit the Webcast page where you can download a PDF file or if you prefer a text file of the slides.

The slides in the computer screen are small. So having the file or a printout could be helpful. On the left side of the screen you will find the chat box. If you have any questions or would like to make a comment please type in to the chat box and I will read your question aloud. Please feel free to ask a question at any time during the presentation. And you can also let us know if you have technical issues and we will try to help you out.

Now I would like to introduce the facilitator Dr. Marcel Dijkers who serves as the leader. Dr. Marcel Dijkers is a research professor in the Department of Rehabilitation Medicine and a senior investigator in the Brain Injury Research Center at Mt. Sinai.

>> MARCEL DIJKERS: Good afternoon, everyone. I hope to get a lot of input from a lot of people today. And I prepared some slides, mostly to get you thinking about the issue. The original question asked by somebody or the issue suggested by somebody quite a few moons ago and a number of the community of practice was indeed being we still call it evidence‑based practice if we deviate from the evidence. But I widened the question a bit by essentially saying what evidence. Because very often we get very little information on what the evidence is. You all know, we all know that presumably the best evidence for evidence‑based practice comes from systematic reviews which ideally developed using a PICO question, population intervention comparer and outcome. Sometimes extended to T, time point of the outcomes and S the setting.

So I grabbed a random recently published systematic review from the literature, Ravi Kumar and Singhi effective of virtual reality rehab for cerebral palsy. And you see here what the authors hope to achieve updating and summarizing the current literature. . They expected that what they reported would be useful to optimize approaches in clinical practice. They specified that they conducted the systematic review using PRISMA. And my sic there indicates that PRISMA is not instructions of ‑‑ on how to conduct a systematic review. It is how to report a systematic review.

And they said they want ‑‑ weren't getting in to meta-analysis. So they had the PICO question, the participants, the intervention, the control which was either in control, control condition of the subject at baseline, or a control group that then presumably didn't get the virtual reality intervention. And the outcomes essentially looked at everything in the ICF.

For each one of the 31 papers they reported they gave information on Watson blue. What was the device and what type of virtual reality, nonimmersive, semi immersive, immersive and input device, output device and duration of sessions and sessions per week and total number of sessions. In red I took the information the authors reported who use the Xbox Kinect which they designated as non‑immersive input was by way of Wii and balance port and remote. There was no output device. Sessions three times a week for 30 minutes, total of 40 sessions. So we got that type of information for 31 papers.

Results with respect to body structure and function, 10 studies found improvement in balance. May be the ones that use the Wii or the Kinect a little bit more. Twelve studies found improvement in upper extremely skills but eight found no change. Two studies improve the lower extremity function and gait. Three or four found improvement in overall multi‑function. Activity and participation it was reported so infrequently and and no clear improvements were reported. Personal factors, no clear. Yep. So pretty much this is the results of a systematic review.

Aside from the fact that you have to say well, is there support for virtual reality or are there so many studies that fail to find that we should doubt it. But even if you say hey, virtual reality is great, what exactly are you supposed to do? And that is not reported. And pretty much if you look at what PRISMA tells you, that you should report on study characteristics, you need to present characteristics for which data extracted, study size, PICO questions, follow‑up period and provide citations. And with respect to the results of individual outcomes, consider ‑‑ sorry, present for each study, a simple summary data for each intervention group affect estimates and confidence intervals, ideally with a forest plot. So it is not that the authors of this particular systematic review deviated from what PRISMA suggested be done. They pretty much did what PRISMA, suggested that to be done. But essentially as a clinician you get almost no information as to well, what am I supposed to do. How many minutes a week, how many sessions a week should I use the Wii or the Kinect Xbox and specifically what programs, apps, et cetera, should I be running, to improve the patience.

Now the question is the systematic reviews, tend to spend a lot of time on describing how they found and evaluated the evidence and very little on presenting the evidence. Do we get more if we go to the primary studies. And do they provide more information on the patient sample, the age, their impairments, their activity limitations, the comorbidities, et cetera. Do we get more information on what was done, who provided it, how, where, when, how much of it was given, whether there was any tailoring of the intervention or in response to individual patient characteristics. . What were the outcomes and when were they administered. And if we follow such reporting guidelines as TIDier. It is an abbreviation for template for intervention description and replication, you indeed get fairly extensive instructions as to what you need to report as a result of doing your primary study. You should provide what information, what materials, what procedures. And I'll leave it to you to scan this for more details. You have to report on who provided it and what was their expertise, background, their generic and specific training. How was it delivered. Modes of delivery. Where was it delivered. location, et cetera, et cetera.

So and then TIDier wants you to provide information on a dose, when was it delivered over the course of treatment or timings since injury onset, something like that. How much was delivered. Intensity dose, et cetera, and then the tailoring, was it one size fits all treatment or was it individualized.

So we have the issue that what's supposedly is the best evidence is systematic review. And we have seen how limited the actual information and recommendations for treatment are after a systematic review. And the problem here may be that the whole idea for systematic reviews came from medicine. And it came from summarizing studies that evaluated drugs, for particular medical illnesses.

Well, for a drug it is very simple to specify what the treatment is and what the dose is. . You just have a generic drug name or a specific brand name and you have milligrams, numbers of time a day, and maybe something like milligrams per kilo body weight. But the story becomes completely different when you are talking about rehabilitation interventions. . What all of you, administer or study or regulate is what typically is called complex interventions. . And you cannot give a prescription with the one liner that a physician, can do it.

. So even in medicine the systematic review, may be supplemented with meta-analysis. May work and may give you some very clear information on what to do for what subgroups of patients, period. For complex of interventions it's more difficult and let's take a typical systematic review and the rehabilitation arena, they generalize over, through to 20 studies, sometimes more. The example in this case had 31. And all of them have yes, somewhat unique inclusion/exclusion criteria. Variations on, the intervention, the duration, total hours. The specific components in a complex intervention. The usual ‑‑ the control group or the comparator group may be different in the 2 to 20 studies, from controlled comparator to usual care, weightless control, those kinds of things. The outcomes considered, may be somewhat different and even if they have the same outcome, the various studies may still use different instruments to operationalize it. Timing may be different in various studies. And the settings, may be somewhat different. So and if you get all of that in a summary that is sparse as we saw before in this particular physiotherapy study, you have little to go on.

And even if your evidence is a primary study, which, may take two or three pages to describe the intervention and the outcome measures and what is measured where and what's the group that was treated consisted of, even if that is a very clear description, and when you as a clinician need to apply it in your patients or if you as a researcher want to do a replication study or want to study some twist on this, you still need to do some, what do you want to call it, adjusting, tweaking, individualizing, for your local resources available, the patients, the staff capabilities and, of course, staff patient priorities and preferences which we have agreed isn't a very valuable component to evidence‑based practice, which leads us, to the question well if you change a CF, you change the evidence. .

The population from what the primary study or maybe the secondary studies said it was, or you change the intervention, or you consider outcomes that were not exactly included in the systematic review or the primary study, or you are interested in time points not considered. And we know that many studies only consider outcomes pretty soon after treatment. And we don't find out much about how good was this intervention in terms of keeping patients that are functioning two years later rather than two days later. If you change these things or some of these things, do we still have evidence‑based practice? Are we still basing ourselves on the evidence? . So the general questions are one, do you in a primary study or more suspect in a secondary study a systematic review get enough information on what the intervention is and how it works for what groups of patients in terms of which outcomes when. You apply that.

Do you get the information. If you have to tweak it, can you still call your practice evidence‑based? And if you say well, it depends on what you are tweaking, what you are changing from the evidence does it depend on whether you are still evidence‑based or not. If you change the nature of the patients, the quantity/quality timing or nature of the intervention, if you shoot for different outcomes, or outcomes at different times or some, other factors.

So there is the questions. And I am looking forward to, getting people's opinions of what they think about this. And how they ‑‑ if they agree or disagree with what you may have heard my stance may be. What is your justification? So you can address with your comments one of the discussion questions or something else. You can add questions. Whatever, you want to contribute to this discussion. Please and you can speak up. And you can type your question in the box on the lower left‑hand side. And I will read, repeat it for the entire group. And if I have an opinion ‑‑

>> JOANN STARKS: We do have a comment. We have a comment from Debbie and Joy. Part of evidence‑based practice includes the expert utilizing the evidence in an appropriate fashion using their clinical expertise.

>> MARCEL DIJKERS: Yes. Well, generally it is phrased, combination of the evidence and expertise. Presumably the expertise is to consider the need to change the evidence. So I am not saying that nobody ever ought to deviate from the evidence. But their question is well, where do you stop being evidence‑based and you are essentially freelancing. And where is it still reasonable to argue that yes, you are based on the evidence, although you are making some modifications in light of the needs of the patient in front of you and/or local resources and some other things.

I doubt it that anybody who is supporting the idea of evidence‑based practice wants to throw out completely the expertise of the people who have to do evidence‑based practice. We may have had defense of that stance 20 years ago where evidence‑based practice was first "discovered". And people in derogatory terms started to talk about cookbook medicine and cookbook physical therapy. We fully well realized that human beings are not meals you put on the table. They are much more complex. And therefore the evidence has to be applied in a setting that takes the person's characteristics and the person's preferences, et cetera, in to account. But yet ‑‑

>> JOANN STARKS: We do have some more questions coming up, Marcel. We are starting to get a list. Can you see them?

>> MARCEL DIJKERS: I don't see them. That's the issue. There they come. Okay.

>> JOANN STARKS: So Linda I think was the next question after Joy and Debbie. So if you can see that, I can read it or you can read it. She had two questions. The first one is what are suggestions regarding the available evidence and how we can use it? Systems are different considering geographical location, unique characteristics of population within the population of study how do we do this. This is what you were talking about. The next one is about the TIDier.

>> MARCEL DIJKERS: The first question I do not necessarily have thought this through enough in all its ramifications to offer you a line in the sand saying this much you can change and if you change one yield you are not evidence‑based anymore. And we will kick you off the island. It is presumably not that simple. And I am not aware whether anybody has done any systematic study where they say took in treatment that was solidly evidence‑based and implemented it for one sample without any change and for another sample with a little bit changed intervention. And for the third one where a little bit changed group of patients, and the fourth one within change of group of patients and the intervention and looked at the outcomes. If somebody is aware of studies like that I would very much say ‑‑ like to hear from you. Sometimes in meta-analysis this is done when a sensitivity analysis or a subgroup analysis is performed and the affected sizes are compared for studies that use 10 to 20 milligrams and studies that use 25 to 50 milligrams, something like that. Again with medicine it is fairly straightforward with complex interventions. There are potentially so many things that you can twist and tweak. It presumably would be much harder to do in the study as I suggested and come up with clear conclusions. So I don't have the answer. I'm not necessarily saying there is an answer, but it might be worthwhile for all of those on this call and maybe your professional organizations to give some attention to this idea. Everyone is jumping on the bandwagon. We do evidence‑based medicine. Well, when does it stop to be evidence‑based? So Linda, I hope that's some useful things to consider.

As for TIDier, TIDier is directed to the people who report primary studies, intervention studies. It was developed by a group in Europe in heavy English majority. They may have all been English and published about three years ago. And essentially they are a guideline for reporting with level items, that they say you ought to report. They are saying you ought to report that. And like is the case with these reporting guidelines they offer justification why it is important and they offer examples of how to do it.

You are linking this to my system. Well, I'm not sure that I am also offering a system. I am asking a bunch of questions. But if you are addressing such issues as well, if we had a number of different studies all of which presumably are based on the same evidence, where can we try to determine were any differences in outcomes as a result from comparing these studies might be a lot easier if all of them did their reporting in terms of TIDier.

The fidelity of the intervention is just one item and, of course, if we set out to test a hypothesis that treatment X is good for outcome Y and we operationalize treatment X in a number of sessions with a number of steps to be taken, et cetera, then we would like to know that the actual implementation of this study indeed yields pretty close to the protocol. And this is where your treatment fidelity comes in. But you could even imagine a study where a brilliant therapist, on the fly cooks up treatment for a unique patient with a unique problem and afterward rights a case study and follows TIDier to your specified what was done. So in a case like we would not have fidelity issues but TIDier would still be a potential benefit use, et cetera, et cetera.

>> JOANN STARKS: You see Ronnie's question? Okay.

>> MARCEL DIJKERS: It seems like practitioners have to make leaps from the evidence to a particular situation. How large a leap is acceptable is the question. And I agree with you, that the question and I may have to give some suggestions as to along what dimensions you can differentiate from the evidence but in the end it is the same story.

Linda, great question. I assume she is talking to Ronnie. What are the alternatives to evidence‑based practice? Well, we could go back to what the situation used to be which pretty much was clinicians who are trained in school. . Got a little bit information about research. Then started practicing and either had their own subscription or their hospital had a subscription to some journals. And a rainy day or when a patient wouldn't show, they would start leafing through the journals and oh, here is an interesting article. And they might or might not be convinced that what was described was a good treatment. And they might or might not apply it. And nobody would claim that they were doing evidence‑based practice. They probably would tell you that they would apply what they learned in school and from their mentors when they were just starting out their professional life.

So there are people, there were people and there are still people that pretty much trash evidence‑based practice as undoable, not good for the patient, cookbook, et cetera, et cetera. But most people and most professional organizations are agreeing that yes, we ought to base our treatments on the evidence. And we ought to, be in the business of evidence‑based psychology and evidence‑based physical therapy and evidence‑based what have you. But ‑‑

>> JOANN STARKS: For instance, if there is a study in people of stroke who have the same impairments as someone with MS I might use that evidence to guide the intervention of the person with MS is that still evidence‑based practice? I think perhaps the way the population is defined is an important variable. Is the population defined based on the diagnoses stroke versus MS or in terms of impairment or functional deficits?

>> MARCEL DIJKERS: Great question. If you are aware with some of the stuff that's being done in evidence‑based approaches especially say the great approach, grade, they judge the evidence and make a distinction between direct evidence and indirect evidence. And if the systematic review wants to collate information on how best to treat people with MS, they may take in some evidence on people with stroke and call that indirect evidence. And indirect evidence never counts as much.

So here is where clinical expertise comes in. Can you extend what has been learned from stroke to say, traumatic brain injury and even prettier question I think is well, should we go with the diagnosis or should we go with the similarity of the impairment that is shared between those two diagnostic groups.

And they are very much I would say the clinical expertise comes in and where I as in prior researchers always have to start back and say well, it is up to you topic area experts to determine whether this indirect evidence has any value. And if so, how much value it does have.

So what I have said, what my slide said about difference in, diagnosis indeed for somebody in rehabilitation might be based potentially better on the impairment's functional shortcoming and that patients has and that the patients in the evidence base have.

>> JOANN STARKS: We have got a lot of questions coming up and only about 15 minutes left here. So another challenge is that the intervention dose provided in the research may not be feasible in clinical practice. For example, not reimbursed at dose, not feasible for the patient clinic. If treatment is provided in the research study five times a week for one hour sessions across several studies, this would be very difficult to translate in to most clinics for many reasons. Is it reasonable to provide a dose that is as close as possible to the research?

>> MARCEL DIJKERS: Yep. Similar studies. Similar questions. We know that research studies, especially if they are supported by a grant very often have the option, the resources, the financial feasibility to offer many more treatment sessions and richer treatment sessions than the poor clinicians in the trenches. So you have to cut back. Very often you are boxed in by what the third party payer will pay for. What is it? 10 occupational therapy sessions on the Medicare per year. blue cross, maybe 15 sessions with a psychologist. I do not blame anybody for grabbing the opportunity to deliver what you can. But you indeed have to ask yourself am I still evidence‑based. Which also brings back a very valuable question, to the researchers among us well, rather than studying what is optimal maybe we should studying a dose that is feasible, practice based and see whether we can create and deliver in those eight sessions or ten sessions something that still has value to the patient.

Okay. Joann provided you with a link to the TIDier guideline itself which then has a link to the article that presented it. Ronnie, if you think of evidence‑based practice as a decision‑making process we can make leaps as long as we are clear that we are sometimes making large leaps and we should engage in more comprehensive progress monitoring. Well, you know, what a good physical therapist I am, Ronnie. And if you publish the systematic review that showed that, treatment X applied to patients with stroke in 20 sessions relieves their knee pain and now I am reading that and I say well, I can't do treatment X because I am not smart enough but treatment X looks somewhat to it. And my patients are not stroke. They have multiple sclerosis and their problem is not knee pain. It is neuropathic pain. I am making big leaps. Is anybody going to grant me the soothing idea that I'm practicing evidence‑based practice? So I'm not sure that being aware that you are making inferential leaps whether small or large resolves the basic issue.

Okay. Joy Williams brings up Sara Keller and Joy and Debbie. I think these point to importance of practice‑based evidence. We probably don't know.

To Jenny's question if approximating the dosage done a recent study will provide the recent benefits. We should be evaluating and sharing findings and constantly seeking additional evidence that can inform interventions. I agree with you, Ronnie, on progress monitoring. Okay. I have no problem with that. And everyone and his brother is encouraging that we, should base our knowledge more on evidence that comes out of regular routine practice than out of research with all the artificiality. The question is how can you do it. And yes, some of you, all of you, many of you may be aware of a series of studies that were done in the last ten years or so called the evidence‑based practice studies. There was the first one in stroke and then joint replacement and then spinal cord injury and then traumatic brain injury. And in these studies we had, therapists after each treatment session fill out a form, on which they summarized what was being done in that session.

It was a major undertaking to have 60 ‑‑ up to 60 therapists in each of 8 or 10 or 14 different sites complete the same form. And that was just for "short term" two years data collection I think study. It is a major undertaking to, have clinicians collect data in a way that can be changed, not just within an institution but across institutions. And I would love to see it. I would love to have it. But it is not that easily done. There are hopes for electronic medical records that they become more useful to clinicians through rehab therapists, and we can have, more common formats, across clinical centers in what people write down. So that we can use that information. So keep it up. Keep trying but it is not going to be that simple.

>> JOANN STARKS: Let me go ahead and see what Jenny wrote down. She is responding to Joy and Debbie. We should collect this information, especially since we don't know the ideal dose for interventions. Use of a core set of measurements and collecting and analyzing this data would help. Joy at the same time wrote I would agree and supports the need for implementing standardized clinician ‑‑ Ronnie says practice‑based evidence is the ultimate criterion of the appropriateness of our inferential leaps.

>> MARCEL DIJKERS: Let me first focus on Jenny and Joy. . We would start at least the journey towards analyzable clinical data collected as part of routine care if we indeed had an agreement on outcome data that were collected by therapists here and in the same discipline and may be across all patient diagnostic groups or, for the diagnostic groups.

And there is a number of efforts that are being taken by professional organizations, special interest groups, and a number of, other people with an interest in and a stake in evidence‑based practice. But I would be very surprised if we asked 50 clinicians to report to us on the outcomes, measures they are using that A, many of them would even use any standardized outcome measures. And if they do, that they would use the same ones or that almost would be many outcome measures used as there are clinicians.

So we have more work to do to get us on the road to truly useful clinician provided outcomes data that can be used to as a basis for evidence.

>> JOANN STARKS: Linda shared the ARLG information exchange link with. It is an interesting link to review evidence and practice. And then we had a comment from Susan responding to Jenny. Agreed that you adapt the intervention to clinical situation as best as possible but still collect outcomes as similar the efficacy study so we can understand the effects. For example, modified CIMT. Some intervention adapted producing almost as strong of an effect.

>> MARCEL DIJKERS: True. Both for CIMT and for others. And that may be because the people who invented CIMT, got themselves on some side roads or did not, maximally understand the more basic science evidence and how it could be applied, et cetera, et cetera.

>> JOANN STARKS: I am getting the last few comments in before we close.

>> MARCEL DIJKERS: I have a very temperamental phone. He hung me up. Claims data generally are so poor in any information both in terms of what was done, to and for the patient and what were the outcomes that you may not find much of anything beneficial in mining them. The other things, electronic medical records that's indeed where I see, the most hope. Because everyone when the treatment session is over, goes to their computer and put some information in. So if the computer, pops up a menu and says okay, from this menu, pick the four, five things you did for the patient and pick the outcomes that you achieved is there standardized outcome measure, click on that. And put in the information. It would be close to painless to provide, the information. And if we all can agree that, either we all use epic or whatever the electronic medical system is they can talk to one another and translate what they have back and forth we should be, getting closer to the, evidence that is based on actual daily practice rather than the sometimes artificial research.

>> JOANN STARKS: This is Joann. Sorry to interrupt. But we have come to the top of the hour. Our CART captioner has to leave. We should probably wrap up and we can probably take a couple of minutes to wrap up. I don't think we have time to address them but it is good fodder for future discussion.

>> MARCEL DIJKERS: Let's do that. It is 4 o'clock and people need to go to other things. We have these pieces of information, the questions and we certainly can see whether any of your additional questions and suggestions open up values for continuing this discussion the next time around. I certainly believe that there is more to be said. Much more to be said. So for now we will harvest everything that people have said. Look at it. And make a decision about how and when to have a next session. For now thank you for your attention. My apologies for the phone running away. Thank God I managed to come back fairly easily and Joann as usual was a great stand‑in. So thank you, Joann. Thank you Ann and the other people at AIR and we will be talking probably in a month to two months. Thanks again.

>> JOANN STARKS: Okay. Thank you very much, Marcel, for sharing this information and leading this discussion. We hope you can take a few minutes by filling out the brief evaluation and we will send out an e‑mail with the evaluation link to everyone who did register. Thanks again for coming today. And I would like to thank the AIR staff for their help and NIDILRR to offer their support and offer these events. We look forward to seeing you for the next event KTDRR. This will be our 2017 online KT conference coming up on October 30th, November 1st and November 3rd. Registration is open and please visit our website at www.ktdrr.org for the details. Good afternoon, everyone.

>> MARCEL DIJKERS: Bye‑bye.